



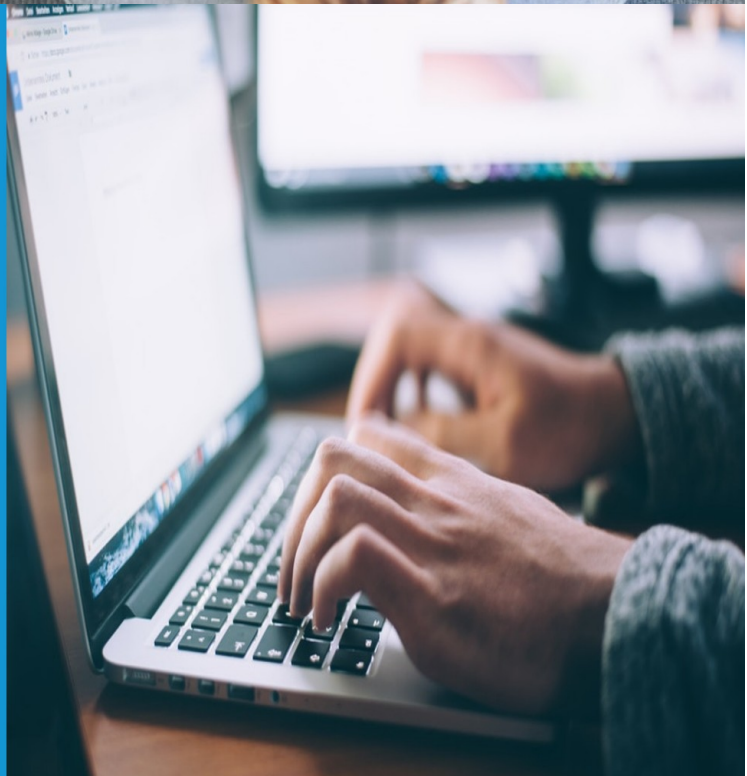
2019 Needs Assessment Report

June 2019

PRESENTED BY



OBJECTIVES AND METHODOLOGY



Objectives and Methodology

The purpose of this study is to understand the needs of those with a brain injury, or their families/providers, and where needs are falling short

Specific objectives include:

- What are the top needs of those with a brain injury
- What they want key stakeholders to understand about a brain injury
- Barriers to receiving services
- Compare key metrics year-over-year

153 online conversations (including both quantitative metrics and a qualitative conversation)

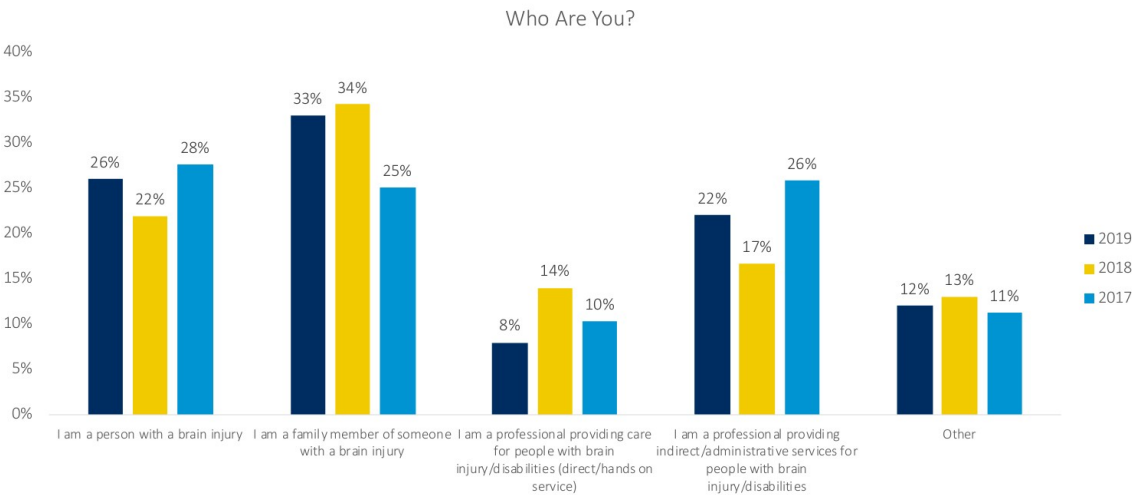
All respondents had some connection to brain injuries and services

Achieved 40 completes from those with a brain injury, 50 from family members of those with a brain injury, 49 from professionals providing either direct or indirect care, and 14 from “Other” relationship



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One-third of respondents are family members while one-quarter are people who actually have the brain injury



Q1: Please help me get to know more about who you are by selecting which of the following statements apply to you.
2017 Responses = 116; 2018 Responses = 114; 2019 Responses = 153

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KEY FINDINGS



Key Takeaways



*[Want community to understand] the **effects a brain injury can have on the person and their surrounding family and friends**. I would like people in my community to **show respect and patience** with people who have experienced a brain injury ... **in the flash of a second it could be any one of us**.*



The most important thing for the community and providers to understand is it requires patience and understanding to work with those with TBI – you can't always see what's going on; everyone and every day is different

Too much red tape with assessments and waivers



They can be confusing and difficult to understand, plus they take too long to get approved



There is an emphasis on wanting to know more about and have better services/funding

People want to know exactly what resources are available and how to get access

Treatment should be **more individualized** – what works for one person doesn't work for everyone else

2019 saw an increase in those citing '**Changes in the ability to work**' as the **hardest part** of a TBI

Especially true among those with BI and Family Members



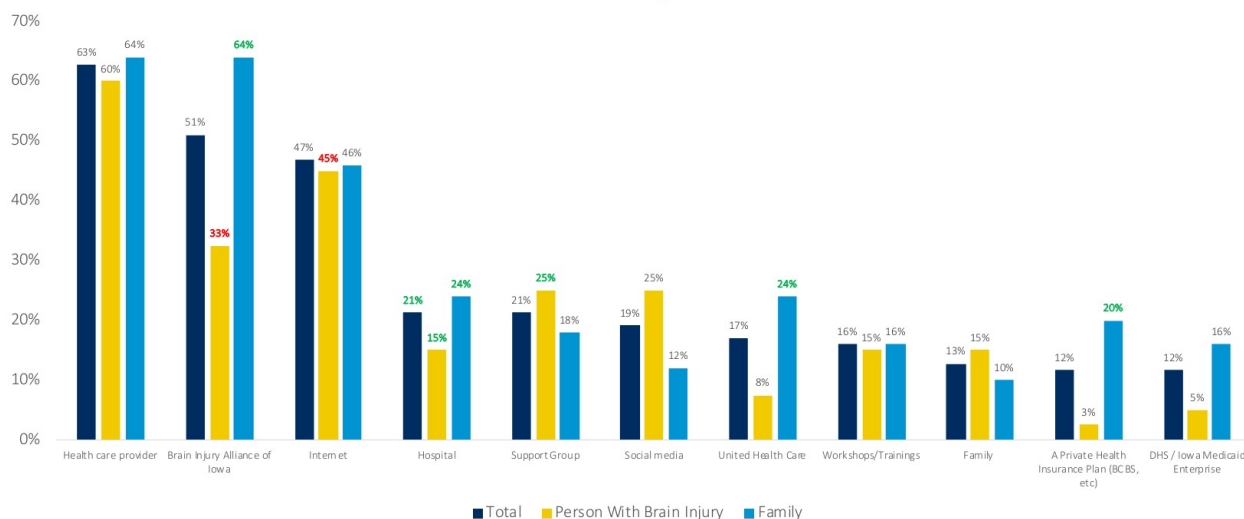
Those who see no improvements over the last year cite a lack of understanding of where to go – they feel isolated because of it ... like they are not getting proper guidance and don't know where to turn



There is a lot of appreciation for the work of the BIAIA – especially when it comes to emotional support and just being there for people

Health care providers, the Brain Injury Alliance of Iowa and the internet are top sources for information

Info Sources – Top 10 & Ties



Q2: First, where do you get most of your health information? n94

*Green indicates number is at least 10% higher than corresponding data point in 2018

*Red indicates number is at least 10% lower than corresponding data point in 2018

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Community needs to be aware of the signs of someone with a brain injury and know how to deal with their actions in a patient and respectful manner

What Should the Community Understand?

Awareness

- Many are 'clueless' and don't understand the impact the injury has on someone – affects all aspects of their life
- Impacts their ability to express themselves, socializing, living situations, relationships with significant others and families
- People need to understand what a brain injury looks like, and how to know and understand what it does

Patience and Respect

- Needing patience as they are dealing with emotional as well as physical barriers, as well as figuring out their new normal
- Extra patience as they may need extra time to process and form how they are feeling (many feel they don't understand since their reaction time is delayed)
- Don't judge – just because they look normal doesn't mean they aren't suffering with a condition or ability to do their job/activities

Everyone is different

- Never goes away, people will always be dealing with the lasting effects of a brain injury
- Understanding that different levels of severity and each individual is different and has different needs
- Even those higher-functioning people with brain injuries still suffer

Inclusion

- Opportunity to be treated like everyone else despite their differences
- Don't deserve to be bullied or abused – "just as deserving of a good quality of life"



Q5: Now I would like you to think about your community, the world around you. Your community may not fully understand brain injury. Thinking about all your experiences, talk to me about what you would like the members of your community to better understand about brain injury. Again, please be as detailed as possible. n152

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Community Should Understand – In Their Own Words

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A person with BI may not appear to have a disability but it can greatly impact their ability to have a job or interact appropriately with others. Concussion is a BI not just an athletic injury.

The community sees the individual slow to process and assumes they do not understand; that he does understand that it just takes a few minutes to process what has been said and to formulate their words in response.

I was shocked by how much my community did not understand. I think that someone needs to tell families of people with brain injury as quickly as possible that after the injury that their loved one may have 'diminished capacity' for some time period and that they need an immediate advocate to stay with them and help navigate the medical issues. Many decisions that need to be made as informal substitute decision makers or formal if needed as the extent to which strong advocates are around the care received by the individual can be dramatically impacted.

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Never judge my son as you often do – saying he is drunk or on drugs. Many people, including law enforcement, have in the past accused him of being drunk. Only to find out his unbalanced walk and slur of words related to his TBI.

They want to be treated as equals and have as much of a chance of employment as any body else. Equals at getting a job in a field of their choice, housing with landlords that treat them with respect. To look past the disability and see the person inside.

How isolating it can be for the patient and family both. The patient may look normal but act inappropriately. Allow more time or awareness of involvement with BI patients. Understand that families and patients are learning a new normal for their routine. They may never regain some functions.

People with a brain Injury do not always 'look' disabled but may need accommodations; but also that it is not helpful to reinforce maladaptive behaviors because you want to be nice.

”



Q5: Now I would like you to think about your community, the world around you. Your community may not fully understand brain injury. Thinking about all your experiences, talk to me about what you would like the members of your community to better understand about brain injury. Again, please be as detailed as possible. n152

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Understanding there are challenges others may not be able to see continues to be the number one concept they want their community to understand

Want Community to Understand -- % Ranked



Topic	Total	Person With Brain Injury	Family	Caregiver/Professional
Brain injury frequently results in challenges and disabilities that others cannot necessarily see	81%	70%	88%	83%
Daily functioning can vary depending on symptoms that are easily affected by stress or medical symptoms	67%	70%	64%	68%
Individuals with memory or language changes are not less intelligent than before their brain injury	60%	63%	54%	63%
Brain injury results have different outcomes and everyone has unique symptoms	59%	48%	64%	62%
After brain injury, the individual may never be the same person they were before	58%	55%	70%	49%
People with brain injury do not need pity but do need compassion and respect	54%	50%	54%	56%
My "main goal" is to live in the community like anyone else as a "member" of my community	31%	33%	34%	27%
To be more aware of the consequences of brain injury	27%	40%	16%	27%
Brain injury impacts how I express myself	24%	40%	28%	11%
To be more aware about how brain injury can be prevented	20%	18%	14%	25%



Q6: Again, using the list below, which of the following are **most important** to you when it comes to what you want your community to better understand about brain injury? n153

*Green indicates number is at least 10% **higher** than corresponding data point in 2018

*Red indicates number is at least 10% **lower** than corresponding data point in 2018

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Medical and rehab providers need to remember that no day is the same for patients and no treatment can do the same for the patient

No day is the same

- Providers need to remember what the patient is dealing with and show compassion towards them, especially since it can be hard to express themselves
 - Having an off day doesn't mean regression – everyone is allowed to have an off day
 - Need to be educated on not just brain injuries but also mental health issues
 - Know where and how the patient and caregiver can receive support

“

Be patient. It is hard to discuss matters or admit there is an issue. Everything you do once you have a brain injury just takes more time. It is hard to adjust to but just be patient.

Not a one-size-fits-all approach

- Healthcare providers need to spend more time with the patient (and talk with the caregiver) to know how the individual was prior to the injury
- Medication can vary for each individual – just because it worked for some, doesn't mean it will work for others
- Providers need to be trained in both mental health as well as brain injury and know the difference

It's more than just treating symptoms. We need more providers of mental health services that are also brain injury trained.

The depression and anxiety don't go away, they just lessen from time to time. Just because a survivor feels better or looks better the symptoms do not go away.

Doesn't go away

- It is something that you have to learn how to live with – it's not like a medical issue that you heal and it's over
- Symptoms like anxiety and/or depression can lessen, but never truly go away

I regularly get the impression that most providers react to my son as though he is mentally deficient as opposed to injured. They need to talk to family and or other concerned advocates as well as spend more time getting to know their patient.

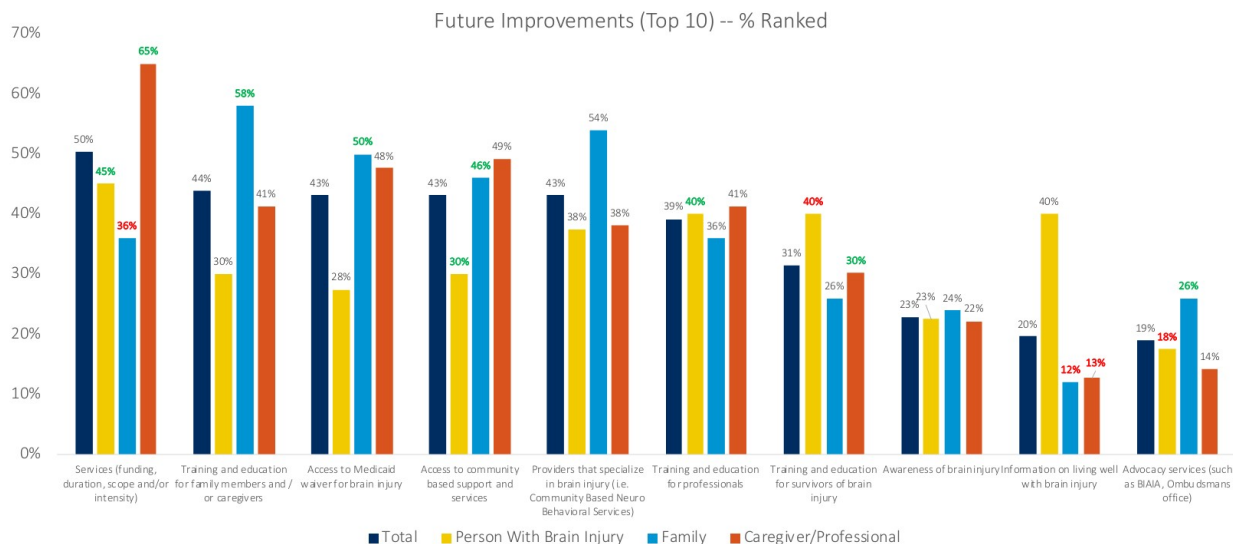
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Q12: Now, let's talk about medical and rehabilitation brain injury providers (doctors, nurses, physical therapists, occupational therapists, etc.). As you think about your experience with these providers, talk to me about what you would like them to better understand about mental health as it relates to brain injury. Again, please be as detailed as possible. n=57

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In 2019, services (funding, duration, etc.) are where most would like to see improvement



Q16: What would you like to see improve about brain injury services in Iowa? n153

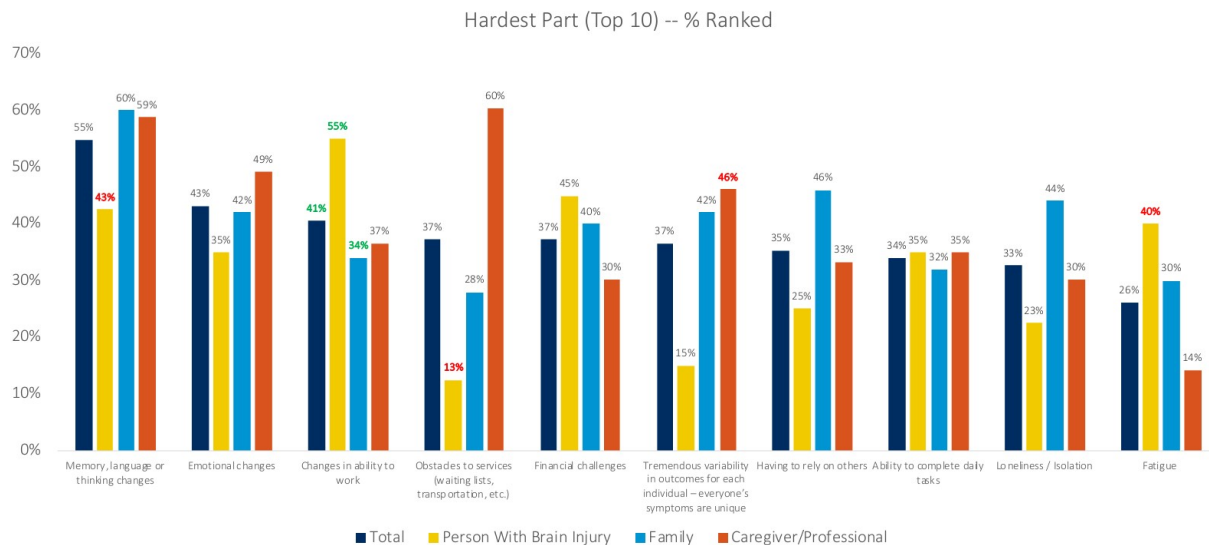
*Green indicates number is at least 10% **higher** than corresponding data point in 2018

*Red indicates number is at least 10% **lower** than corresponding data point in 2018

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Memory and language/thinking changes continue to trend down for people with a brain injury, but still remain the hardest part



Q18. In your opinion, what are the hardest or most challenging things about brain injury? You may rank up to 5 options. n153

*Green boxes indicate number is at least 10% higher than corresponding data point in 2018

*Red boxes indicate number is at least 10% lower than corresponding data point in 2018

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For those creating public policy: available services from the start is key; improved assessments and less wait time for the BI waiver

Services and Resources Available

Services and resource information need to be available from the start:

- Need lists of available resources and services before leaving the hospital
- Services should encompass: recovery; life readiness; emotional coping; memory loss; employment skills; exercise; social interaction
- Easy and immediate access
- Doctors, nurses, PT are often unaware of what resources are available – they need to be educated
- Centralized intake would be ideal

Additionally ...

- Best-practice therapies need to be included with other nontraditional therapies: HBOT; nutrition counseling; therapeutic light; etc.
- More providers in the state of Iowa – specifically more BI specialists

Eligibility and Assessment Processes

Assessment/Eligibility processes and forms are inconsistent, confusing and need to be fixed. Streamlining is key

- Assessments need to be consistent
- Need to be filled out and processed by knowledgeable brain injury doctors
- Disability eligibility – especially at the federal level – needs reformed
- Assessment needs to happen individually and not lumped as a group
- Should include caregiver feedback
- Should include many types: cognitive assessment; employment skills; etc.

More Services Covered by Insurance

Brain injuries are not “cured.” Time limits should not be in effect and critical services should not be denied by insurance—especially based on slow progress

BI Waiver

- Decrease the waitlist time – up to 2 years is “ridiculous,” “unacceptable”
- Needs to be fully funded – no caps
- Waiting lists are “detrimental to the outcome” -- hinders recovery efforts
- Red tape paperwork for waiver is too cumbersome – need advocate to assist the “common” person/family

More Funding

Additional funding is necessary to support BI survivors, including their unpaid caregivers and families

- Resources funneled to more services and less administration with its corresponding “roadblocks”
- Aid in the beginning saves money in the long run
- Families are “doubly burdened:” loss of job and cost of medical treatment

Advocates

- Assigned to each person - provides information, follow up and helps find services and resources to fit needs
- Help with extensive paperwork – survivors often “give up” on filling out documents
- Ideally, someone there for the “full process” as their one point of contact

Caregivers

Critical to listen to the caregivers regarding daily life of BI survivor and make sure the advocate is also checking in on the caregiver

Important to offer services and resources for families – financial, emotional and peer resources to cope



Q25: We have talked a lot about what you would like others to know more about relative to brain injuries. Now I'd like you to imagine that you could speak directly to those in charge of creating public policy and services for those with brain injuries. (For example improve the ease of the application and eligibility determination process, have brain injury specific assessments for people with brain injury). Let's say you were a key advisor. What would you say to them to make policy and services better for you? n153

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Message to Policy Makers – In Their Own Words

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When a person has been working and loses their job due to a brain injury there needs to be financial assistance. As a caregiver I did not qualify but with the extra expenses in transportation and caregiving I am losing my home because of his lost income. He was renting from me and suddenly I am caring for him. It put a strain on our relationship and finances.

Find a way to get the waiting list down from two years. Have specific assessments for brain injury persons. Assign and support an advocate for each brain injury survivor.

We need better healthcare and community support. Just because we are still waiting on SSDI shouldn't prevent us from getting the brain injury waiver program. I need more options for those of us considered higher functioning too. These brain injuries disable us in our daily functioning and we are acutely aware of our losses. We need integrated medical care for the long term. We need consistency in getting disability determination for benefits. How can I be considered in the most significantly disabled category based on my medical records for Vocational Rehab but then the same organization that determined this says I don't qualify for SSDI benefits because I can still move my arms and legs?



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Stop the 'silo' of waivers. Add them all together, fund them and assess each individual appropriately.

Get people the services they need right away. No waiting for eighteen months. You would never tell someone with cancer that they had to wait eighteen months for treatment. Waiting creates more problems

I would like to make sure that no one is let out of the hospital with a TBI that has not spoken with a social worker OR similar person about living with a TBI. They should be given information packets from the BIA if they are here in Iowa. I had none of the above when I was released from the hospital. I was in an induced coma for a few days - so I think that I was in fairly serious condition.

1. Provide leadership and guidance to caregivers of TBI survivors.
2. Hook caregivers up to a team of professionals to guide and be resourceful as to the next step . 3. We need psychiatrists, neurologists, psychologists, primary care doctors that understand TBI. As caregivers we are floundering and using every resource we can find. There really are none.



Q25: We have talked a lot about what you would like others to know more about relative to brain injuries. Now I'd like you to imagine that you could speak directly to those in charge of creating public policy and services for those with brain injuries. (For example improve the ease of the application and eligibility determination process, have brain injury specific assessments for people with brain injury). Let's say you were a key advisor. What would you say to them to make policy and services better for you? n153

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ADDITIONAL FINDINGS



Disability Service Professionals seem to lack full understanding of what a brain injury is and how it affects the patient and their life going forward

What Should Disability Service Professionals Understand?

Staff needs to be more knowledgeable

- More knowledge dealing with best practices
- Staff seems to lack training and has a hard time understanding behaviors, abilities, and challenges – need to focus more on truly validating their feelings and acknowledge their need for support
- Educating professionals on how nutrition can help symptoms as well as reversal of the underlying issue
- “Need people who know their way through a maze”

Good days and bad days

- Patients may have good days and bad days, it is non linear when it comes to the nature of rehab and recovery
- They need another set of ears to come with them for discussions of health and recovery matters
- Encourage them to keep being active and involved in life activities

Just because they look normal

- Brain injuries may not always be easily visible or immediately obvious – may appear like nothing is wrong but it is there and impacts their lives daily and never goes away, always dealing with it
- Many feel lumped into the same category of severity when in reality, every person's case is different

More support and coping methods

- Need to know how to navigate their new world and don't know what services are offered to them
- Activities to be involved in with people dealing with the same injuries
- Workshops for those who are dealing with someone with a brain injury so they know how to help or give emotional support



Q3: Let's talk about disability service professionals (i.e. case managers, service coordinators, direct care staff, home health aides, etc.). As you think about your experience with disability service professionals, talk to me about what you would like them to better understand about brain injury. n152

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Disability Service Professionals Should Understand – In Their Own Words

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That we have good, bad and really bad days. We make choices or decisions that are out of context with our character. Most of us are suicidal. Being able to think on an even level. Not stretching for words or comprehension is a good day. Bad is the opposite of this.

People with TBI used to have 'normal' lives before their life changing injuries. Many lack motivation due to the injury. Keep encouraging them to stay active. I have known many people with TBI who withdraw from life and stay in the house or asleep too much. Encourage them to stay involved in life activities.

More suitable jobs. More social activities with other services to place with similar injuries. My son is socially functional. He is able to do self care and live on [his] own. He needs help with transportation, banking, and speech at times but he is very social and funny and liked by all. The services we use have lower functioning people. My wish is have persons he could go places with like movie, dinner, hang out, and talk.



“

How it changes a person's ability to do what they once could. How someone can appear to have nothing wrong but struggle with loss of ability to concentrate, comprehend, process and retain information.

The causes and changes in PT's behavior and cognition. Behaviors not typical from frontal BI. Thinking skills are not up to par and they may need decision makers going forward.

Fear and confusion of having your total world disrupted as the result of a BI. Needing to learn how to navigate the new world with out adequate tools. Staff lacks understanding and adequate training. They need to know recovery is individual, uneven and different for each individual. They need to know what to do to handle changes and behaviors resulting from these challenges and the environment. They need empathy that comes from understanding. The BI does not change intelligence but changes emotions, physical and functioning.

It is a lifetime. Most of the time it does not get a lot better for many who experience it.

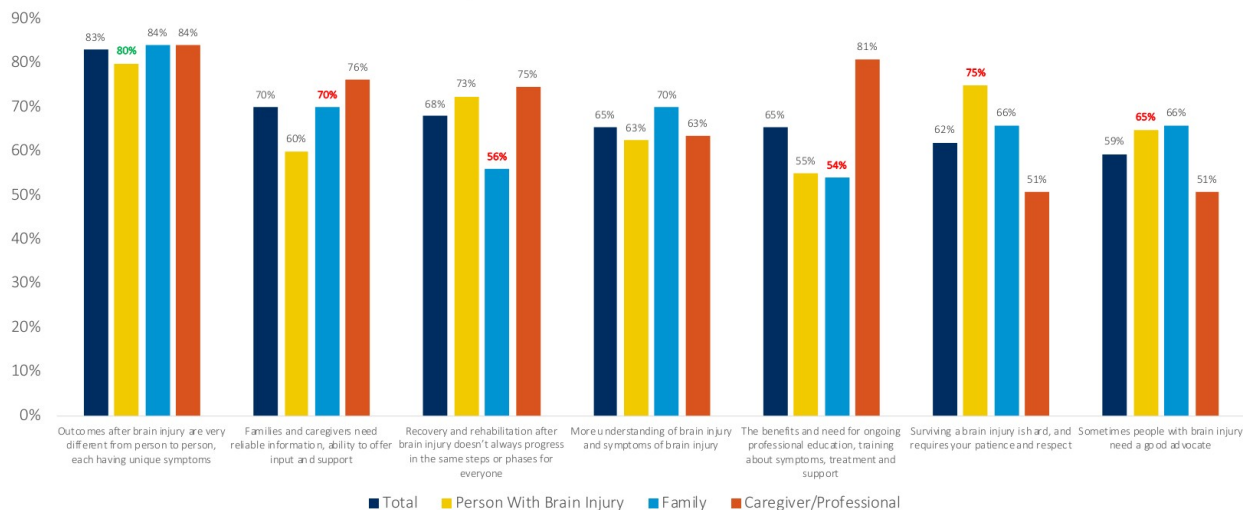


Q3: Let's talk about disability service professionals (i.e. case managers, service coordinators, direct care staff, home health aides, etc.). As you think about your experience with disability service professionals, talk to me about what you would like them to better understand about brain injury. n152

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Knowing outcomes as well as rehab vary from person to person and needing more reliable info rise to top again in 2019

Want Disability Service Professionals to Understand -- % Ranked



Q4: And, using the following list, which of the following are **most important** to you when it comes to what you want disability service professionals to better understand about brain injury? n153

*Green indicates number is at least 10% **higher** than corresponding data point in 2018
*Red indicates number is at least 10% **lower** than corresponding data point in 2018

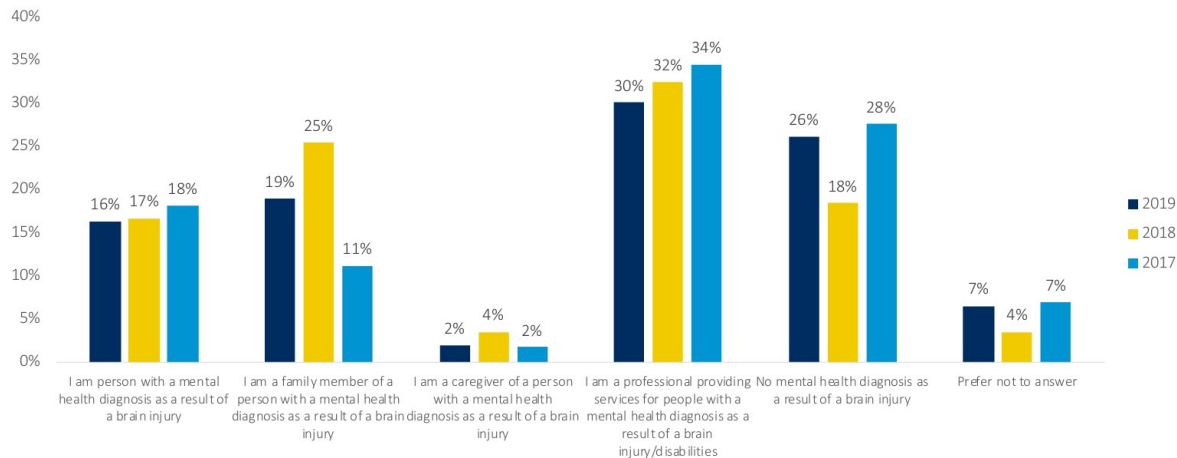
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In 2019, two thirds had some connection to a mental health diagnosis, compared to nearly 80% in 2018

Mental Health Diagnosis

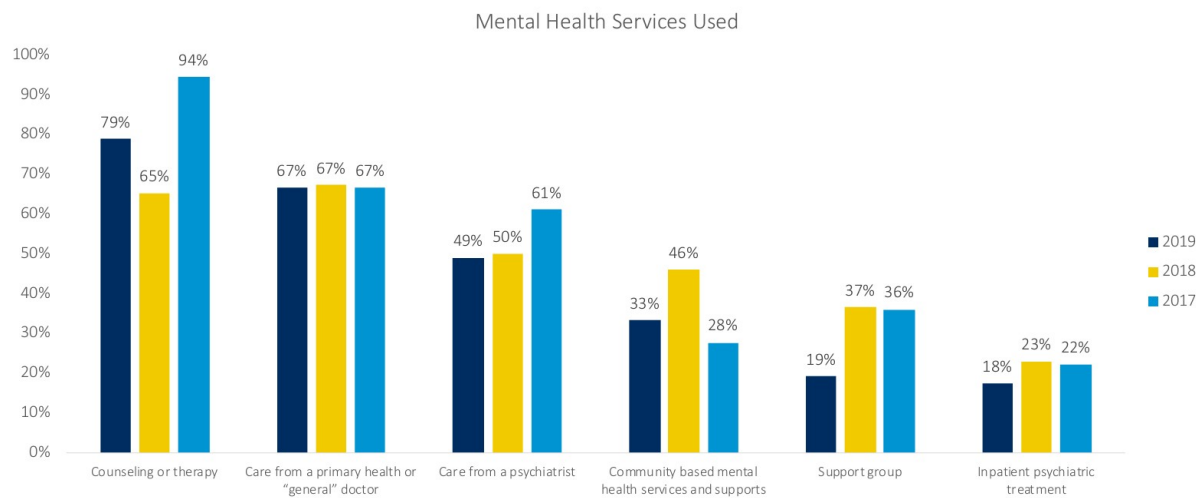


Q7: I'd like to know a little more about you. Tell me, which of the following statements best describes you?
2017 Responses = 116; 2018 Responses = 114; 2019 Responses = 153

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More cited counseling or therapy compared to 2018; 2019 saw an increase in support group mental health services



Q8: Since [insert your/your loved ones/those you care for experienced a] brain injury, have [insert you/they/they] used any mental health services and support? 2017 Responses = 36; 2018 Responses = 52; 2019 Responses = 57

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Mental Healthcare Providers need to be more educated on the issue and understand how to not only help the patient but the family as well

Need More Education

Need more education on brain injury conditions as well as how to treat brain injuries

- Requiring more education before completing a degree
- Able to identify a problem, even if not showing up in routine exams
- Many levels and ranges of injuries

Understanding how brain injuries change over time

- Open to learning new or alternative perspectives on how to deal/treat the injury

Hard to Find

- It is an ongoing challenge to find support and doctors that truly understand and don't just want to put the patient on meds
- Providers are difficult to find and often don't stay at the same practice for long; puts stress on the patients and/or their caregivers due to constantly catching the doctor up on their condition
- Providers can be particular about who or what conditions they will see

Having Patience

Need to understand and be respectful and patient while listening to the patient – it can take them longer to put into words how they feel

- It can be hard for them to express themselves

Look at Them as a Person

- Don't want to be treated as a child
- Not being treated like they don't have any rights

Help Not Just the Patient

- Educate them as well as their families on how to live and cope with a brain injury
- Being able to give the families or caregivers helpful suggestions on how to handle hard situations



Q9: First, let's focus on mental health providers (counselors, psychiatrists, psychologists, etc.). As you think about your experience with mental health providers, talk to me about what you would like mental health providers to better understand about brain injury. This is your opportunity to help us improve mental health services, so please be as detailed as possible. n=54

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Mental Healthcare Providers Should Understand – In Their Own Words

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Mental health professionals need information about brain injury too. They may not be up-to-date on brain injury issues. Everyone gets comfortable in their own box and stretching their minds to learn new or sometimes alternative perspectives that may run counter to their current livelihoods may be difficult or inconvenient.

Although mental health care providers may be able to treat the symptoms they should have a complete and thorough understanding of the brain and how affects of injuries may change over time.

It is difficult to find a good fit for the brain injured person. They can be difficult and choosy on who sees them. We went through many therapists.

It is an ongoing challenge to find behavioral support only in that our son has so many health challenges - brain injury from birth III and IV, cerebral visual impairment. Not many are familiar with this; needs to be better information readily available to all CP ADHD and hydrocephalus.



“

Would like to see counselors trained in providing more coping skills to the brain injured person and their family members. So they can help teach how to cope with this mentally on a day-to-day basis.

I see people that have specialized in brain injury. It can be hard to communicate what I am going through and dealing with. Just being respectful while I try to process my thoughts.

Some symptoms are invisible and don't show up in a routine exam. Stress can make a TBI worse and PTSD can make it even worse.

Further education is essential. So many are clueless. They lack understanding of the severity of mental illness especially with a brain injured survivor. My recent hospitalization was horrible.

Once again, family members need to be kept informed and may have many questions quite often. Mental Health providers tend to avoid any 'informational' type conversations like they don't have time.

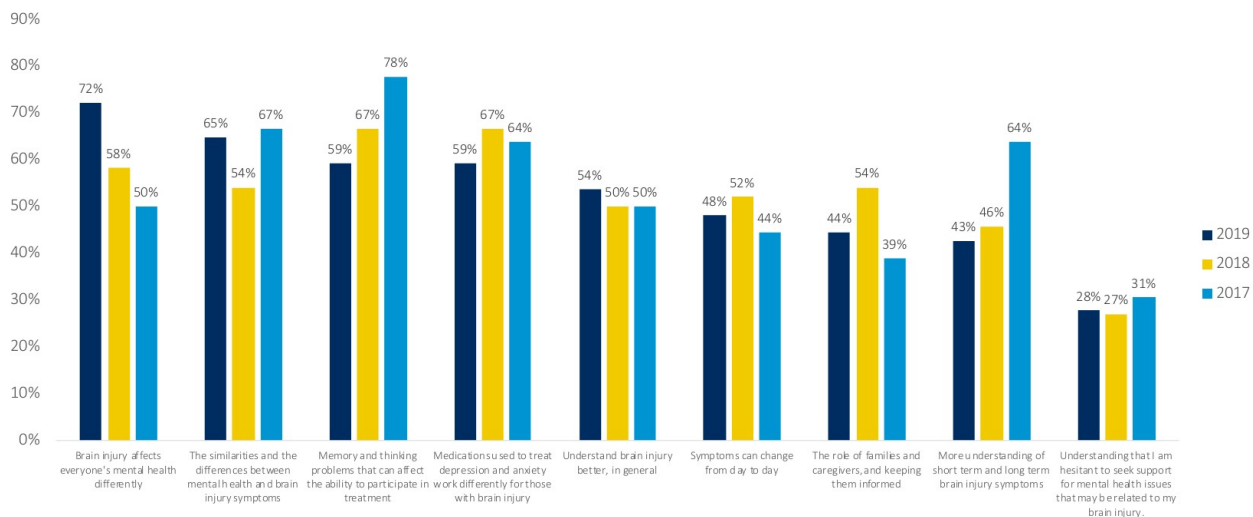


Q9: First, let's focus on mental health providers (counselors, psychiatrists, psychologists, etc.). As you think about your experience with mental health providers, talk to me about what you would like mental health providers to better understand about brain injury. This is your opportunity to help us improve mental health services, so please be as detailed as possible. n=54

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2019 saw an increase in wanting providers to understand that brain injury affects everyone's mental health differently

Want Mental Health Providers to Understand -- % Ranked

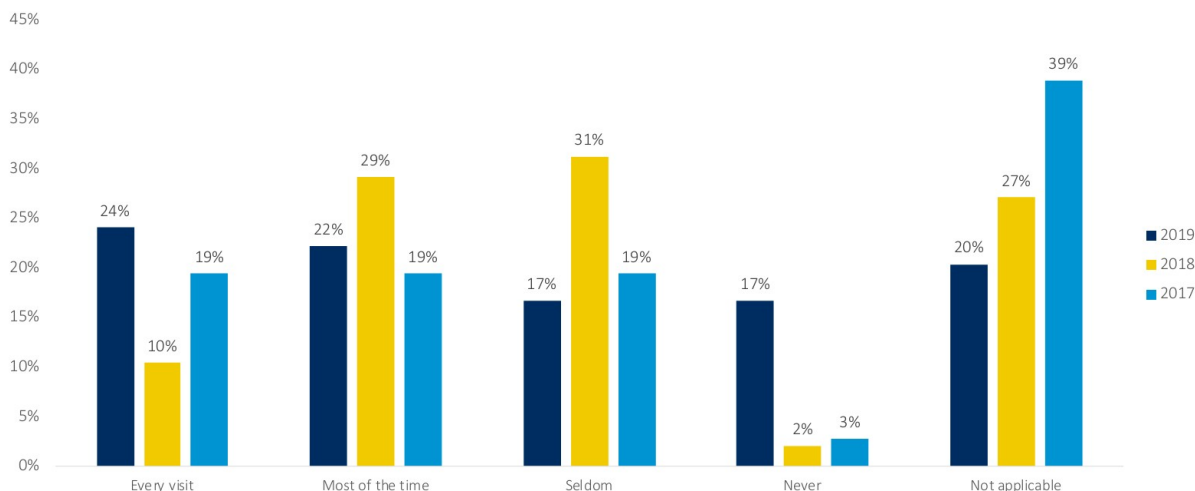


Q10: Just to make sure I understand, using the following list, which of the following are **most important** to you when it comes to what you would like mental health providers to better understand about brain injury?
2017 Responses = 36; 2018 Responses = 48; 2019 Responses = 54

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In 2019, more of those who see mental health providers are being asked every visit about other conditions (although more also say they are never asked)

How Often Mental Health Providers Ask Questions About Other Conditions

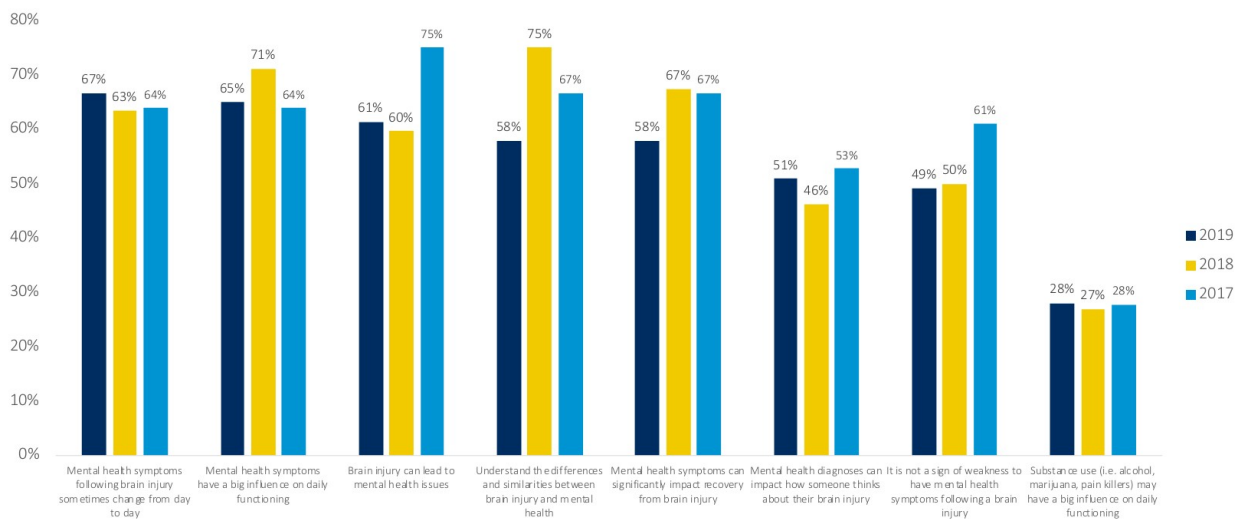


Q11. How often does your mental health provider ask questions about other conditions you might be experiencing, such as brain injury, substance abuse, and physical conditions?
2017 Responses = 36; 2018 Responses = 48; 2019 Responses = 54

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In 2019, the most frequently ranked option for brain injury providers to understand about mental health is that symptoms change from day to day

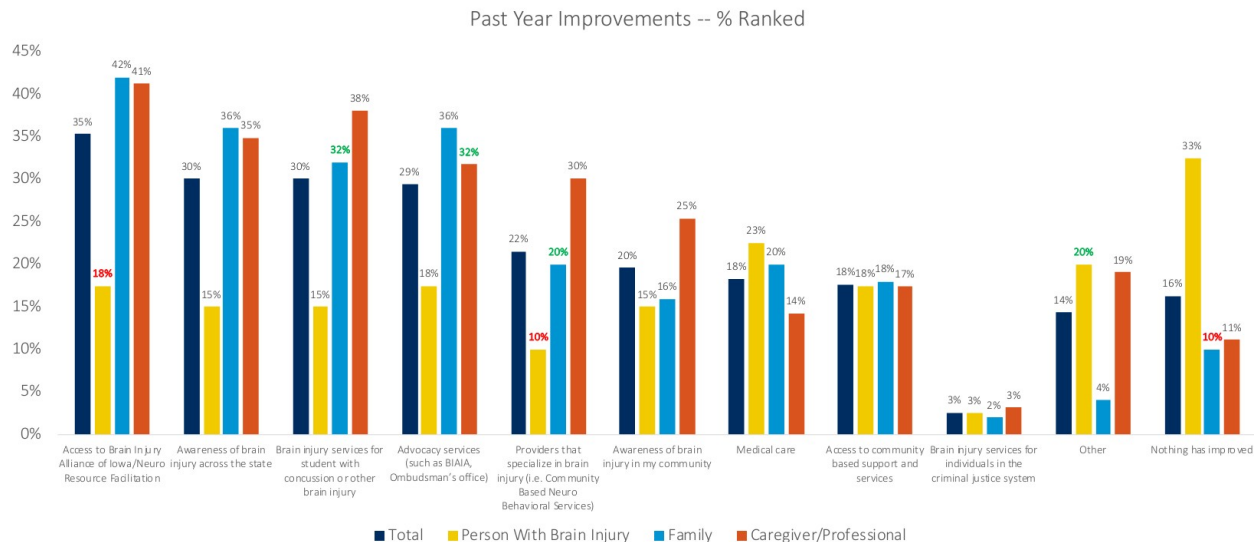
Want Medical and Rehab Providers to Understand About Mental Health-- % Ranked



Q13. Using the following list, which of the following are **most important** to you when it comes to what you want medical and rehabilitation brain injury providers (doctor's, nurses, physical therapists, occupational therapists, etc.) to understand about mental health? 2017 Responses = 36; 2018 Responses = 52; 2019 Responses = 57

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Overall, more than a third say access to the Brain Injury Alliance of Iowa has improved in the past year (although lower among people with brain injury)



Q14. Now, thinking about brain injury services in Iowa, which of the following have improved in the past year? n153

*Green indicates number is at least 10% **higher** than corresponding data point in 2018
*Red indicates number is at least 10% **lower** than corresponding data point in 2018

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Lack of improvement hinges on not knowing where and what services are available – feel isolated when they do not provide info

Why Feel Nothing Has Improved?

- Do not know where to go for services and support
- Often feel they are searching, planning and navigating the process alone. They feel isolated
- Little guidance from hospitals, doctors and staff from the onset of the brain injury
- Hard to navigate services: Medicaid, Medicare, SSD and BI Waiver – continual (exhausting) fight for benefits
- Lack of BI specialists in Iowa – need more doctors, mental health providers, direct care workers who are knowledgeable in the field
- Less services covered by state and federal funding
- Support groups, resources, and help for those who are high functioning
- Some are unsure if there has been improvement because brain injury is rarely discussed



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Fortunately, because we are both professional social workers, we knew a lot about how to get our needs met but we still could have benefited from more education and linkages to BI related resources and support. The hospital didn't help us connect with any such resources, rehabilitation staff didn't take any pro-active role in trying to connect us to those resources, and the PCP – although an outstanding physician – didn't know of the resources or didn't make any effort to get me or my loved one connected to any.

We personally have not tapped into brain injury services over the past year any more so than previously. However trying to use our waiver services has become more difficult due to constantly changing providers and Managed Care Organization.

Mental health services have decline overall in the last year. More people are being diagnosed and treated for mental health issues with a severe lack of appropriate health care professionals specialized in mental health brain injury.

If anything, Iowa has moved backwards in services covered by federal or state funding.



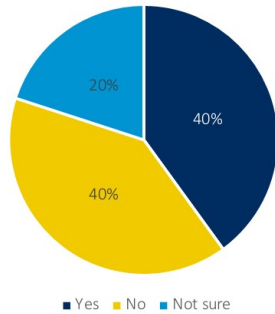
Q15: I am sorry to hear that you feel nothing has improved in the past year. Help me understand why you feel that way? Tell me about the struggles you are facing relative to these services. n25

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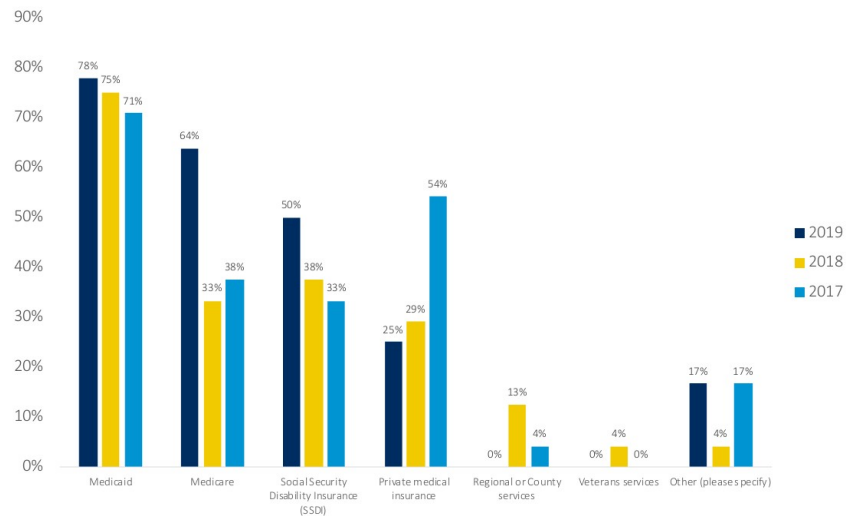
28

40% have funding for services; 2019 saw an increase in those with funding from Medicare and Social Security Disability Insurance

Do You Currently Have Funding?



Which Do You Have?

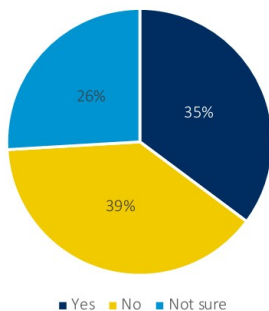


Q20. Do you currently have funding for services? 2017 Responses = 61, 2018 Responses = 64, 2019 Responses = 50
 Q21. Which of the following do you have? 2017 Responses = 24, 2018 Responses = 24, 2019 Responses = 36

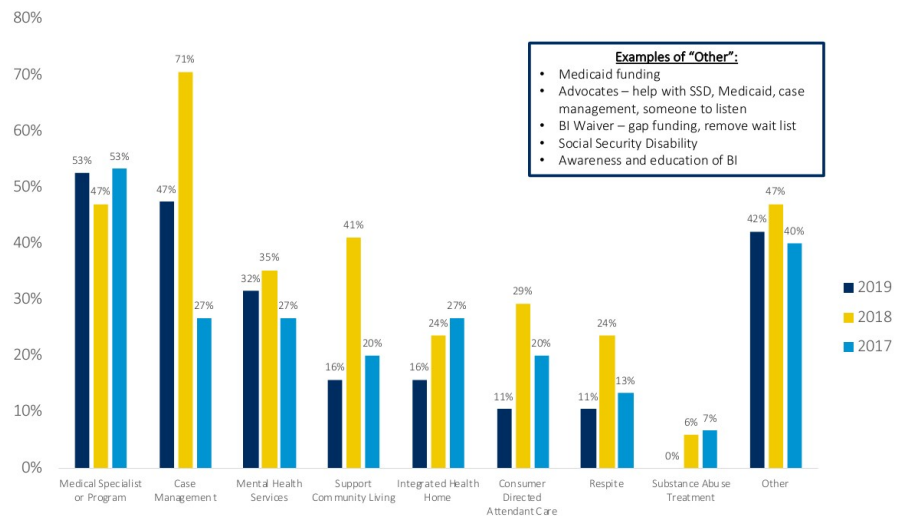
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35% are waiting too long for services (compared to 43% in 2018) – they are waiting too long for a medical specialist/program and case management

Forced To Wait Too Long For Services?



For Which Are You Waiting Too Long?



Examples of "Other":

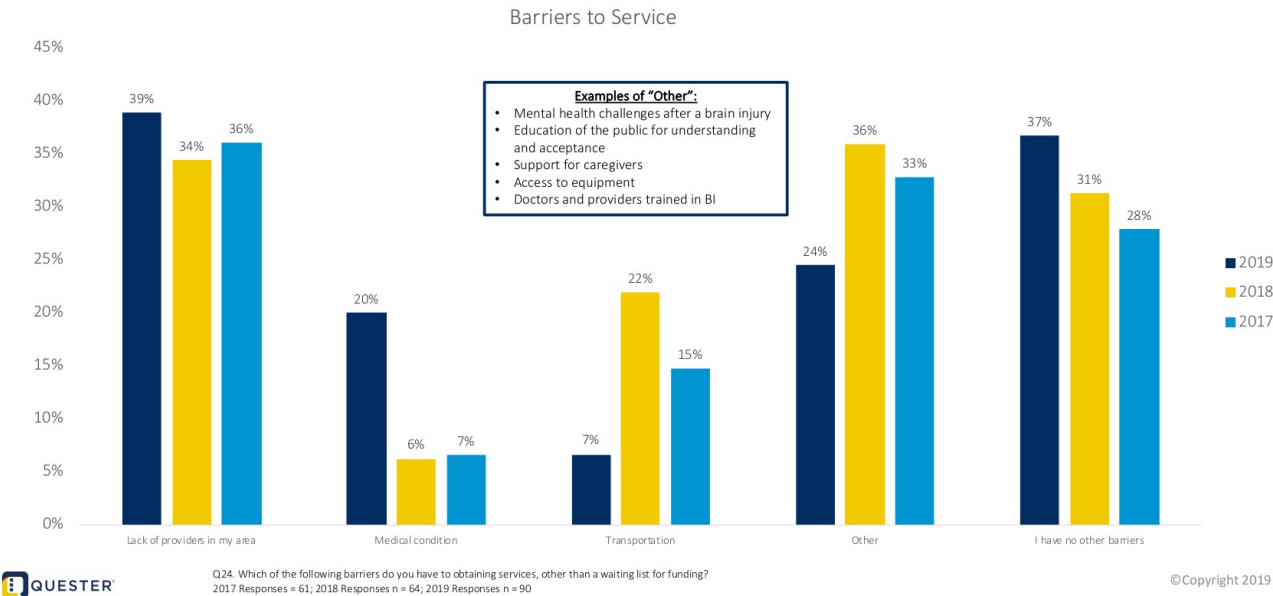
- Medicaid funding
- Advocates – help with SSD, Medicaid, case management, someone to listen
- BI Waiver – gap funding, remove wait list
- Social Security Disability
- Awareness and education of BI



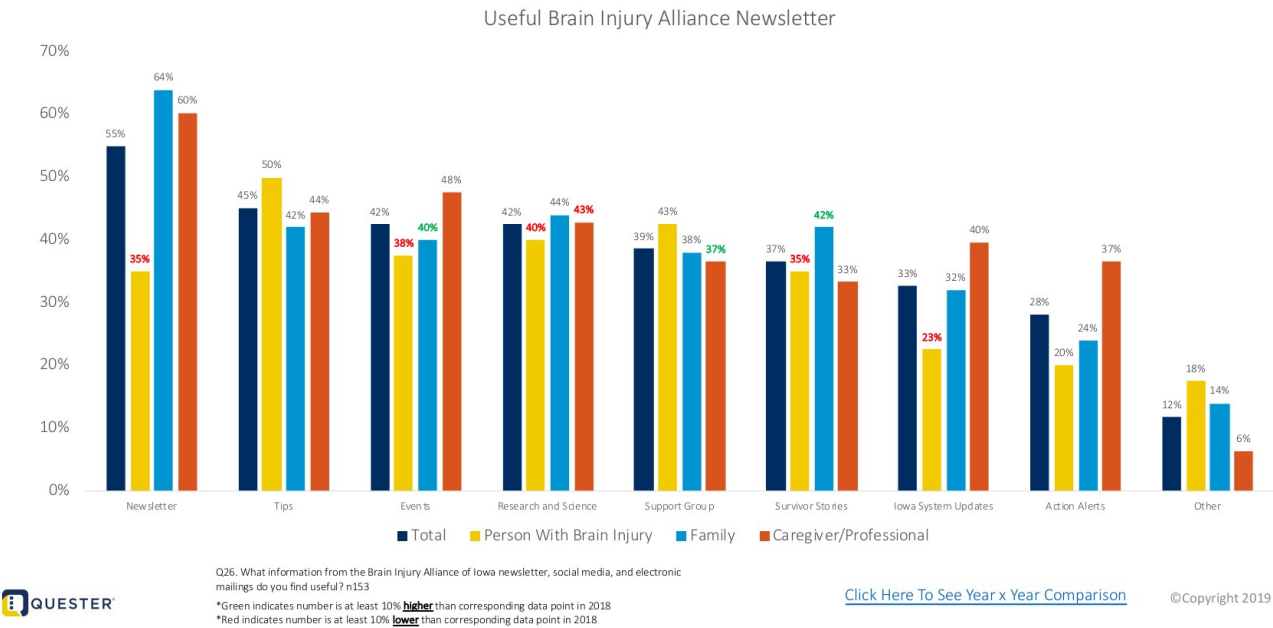
Q22. Are [insert your loved ones/those you care for] forced to wait too long for needed services? 2017 Responses = 37, 2018 Responses = 40, 2019 Responses = 54
 Q23. For which services are [insert your loved ones/those you care for] waiting too long? 2017 Responses = 15, 2018 Responses = 17, 2019 Responses = 19

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The biggest barrier to service is lack of providers in the area; 2019 saw an increase in those saying a medical condition is a barrier



The newsletter, tips, events and information about research and science are found to be the most useful information from the Brain Injury Alliance



Additional thoughts include better education and awareness around brain injury and the need for more support

Education

- Lack of awareness and understanding regarding brain injuries
- Critical information including the signs of injury
 - Importance of seeing a doctor if head is hit, injured or jarred in any way
 - Prevention of brain injury

Understanding brain injury survivors

- Many levels and ranges of injuries
- BI survivors can have functioning lives
- Often a lifetime condition that isn't cured but managed
- Often not one "standard fix" and outcomes are varied
- Individuals are affected in multiple ways: "It's a different world for every victim every time."

More Support and Services

- Reliable, appropriate services need to be in place and survivors and their families need to know where and how to get help
- More support groups are necessary for the brain injured individuals
 - Emotional help for the caregiver and the family including support groups
 - Advocates need to be assigned to help with multitude of tasks
 - Better integration and support to get back into the community and back to employment

More Specialists

- Better educated and trained specialists in medical care across the board
- Doctors and specialists need to be "flexible and creative" in treatments

Emotionally Difficult

- Feelings of loneliness and isolation
- Often hard to communicate thoughts and feelings – patience is required
- Long to get "back to normal," get back to the community and flourish again
- Remember what life used to be like
- Feels "unfair to rest of my family"
- Often "pleading for services"

We're Hopeful

- "Every person wants purpose in their life"
- Living a fulfilling life after a brain injury is possible
- Caregiver needs to "roll with things," be patient and have a sense of humor



Q28: Thank you for all your help today! Before we wrap up, I wanted to give you one last opportunity to tell me anything you feel is important to know about brain injuries that I haven't already asked you about. n152

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Additional Thoughts – In Their Own Words

“

Need support support support.

As far as I know [BI] only came to light when we realized the pro football players were having issues, research on autopsies, etc. My friend fell on the ice and hit her head. 'I'm OK' she said to her son in law who's an MD. "We are going to the ER," he said and forty five mins later she was in surgery with a bleed. I feel the general public needs to know to get examined after a head trauma even if they feel OK. Flyers around EVERYWHERE like the are for stroke and heart attack. Getting help quickly MAY save many from severe results.

Brain injury takes a lot of courage to live with.

Maybe a little more information or support for caregivers would be helpful. We find the support group very helpful. Sometimes I feel kind of alone – don't think my friends really understand what we are going through.

We need access to advocates whether it deals with a legal issue that can provide income benefits help etc.



“

It is important to serve those individuals that have a great need but don't forget those of us who struggle with seemingly small deficits. The mountain is just as high and tough to climb.

Brain injury has changed everything about my life. In fact it's like starting over learning how to effectively be alive. One of the most difficult things is wondering if I'll ever find a way to fully participate in community again.

Primarily the lack of services and trained professionals in N. E. IA. The current training requirement for individuals to service BI is not adequate. More funding and access to the BI Waiver and outreach and education availability. More everything.

The struggle is real but just keep moving forward

Caregivers and family members need support as much as the brain injured person themselves.

That we as a community need to group together to make persons with brain injuries feel part of the community and not as outsiders.



Q28: Thank you for all your help today! Before we wrap up, I wanted to give you one last opportunity to tell me anything you feel is important to know about brain injuries that I haven't already asked you about. n152

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Additional Thoughts – In Their Own Words

“

Thanks for all the good work being done by the BIA of Iowa and for being a great resource to anyone impacted by a brain injury.

The Brain Injury Alliance of Iowa is an amazing organization. Someone on the team has called me for over seven years to see how my son and I are doing. Thank god you are there.

I believe I have covered all of the points I wished to make. I would also like to say Thank You to the Brain Injury Alliance of Iowa for all of the assistance I have been given the past two years. The education, support, especially emotional as well as offering suggestions, etc. The tote bag I was gifted when my son was in the hospital was so very helpful and greatly appreciated. I will continue to support to BIAIA.

Advocacy is the key. Thanks for representing those with and those touched by brain injury.

”

“

Thank you for the commitment to recognize this population and the importance of providing appropriate services to them.

Thank you for taking time and effort to improve the communication in Iowa about brain injuries.

Thank you to your group and all you do for those affected. We are fortunate to have good overall support for our son in this state and our community.

My experience in using the brain injury of Iowa services was that they provided a crucial and invaluable support at a very difficult time in my family's life and I cannot thank them enough for all of the help and resources which they tirelessly provided when we were at a critical juncture in the care for our son's best possible treatment.

Thank you for advocating for brain injury.

”

Q28: Thank you for all your help today! Before we wrap up, I wanted to give you one last opportunity to tell me anything you feel is important to know about brain injuries that I haven't already asked you about. n=152

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42 different counties in Iowa represented in 2019, with Polk accounting for 19% and Johnson/Linn each accounting for 12%

Gender

Gender	Percentage
Male	26%
Female	74%

Age

Age Group	Percentage
Under 35	11%
35-44	12%
45-54	26%
55-64	35%
65+	16%

* Counties in blue had at least 1 person complete the survey
* 3% do not live in Iowa

D1: To wrap up today, I have just a few questions that will help us better understand who and where you are. n=153
D2: What is your age? n=153
D3: What is your gender? n=153

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online.fliphtml5.com/btqhs/ksvm/#p=4

18/23

APPENDIX: YEAR-OVER-YEAR COMPARISONS



Sources of Info – Year-Over-Year Comparison

	Total			Person with BI			Family Member		
	2017	2018	2019	2017	2018	2019	2017	2018	2019
	61	65	94	32	25	40	29	39	50
	A	B	C	D	E	F	H	J	K
Health care provider (i.e. a doctor or nurse)	51%	60%	63% A	50%	56%	60% D	52%	64% H	64% H
Brain Injury Alliance of Iowa	49%	52%	51%	50% F	60% DF	33%	48%	46%	64% HJ
Internet	51%	55%	47%	47%	60% DF	45%	55%	51%	46%
Hospital	21% B	8%	21% B	22% E	4%	15% E	21% J	10%	24% J
Support Group	21%	15%	21%	22% E	12%	25% E	21%	18%	18%
Social media (Facebook, Twitter, Pinterest)	16%	25%	19%	19%	32% D	25%	14%	21%	12%
United Health Care – Managed Care Organization for Iowa Medicaid members	2%	12% A	17% A	0%	12% D	8%	3%	13% H	24% HJ
Workshops/Trainings	23% B	12%	16%	13%	12%	15%	34% JK	13%	16%
Family	13%	9%	13%	16%	12%	15%	10%	8%	10%
A Private Health Insurance Plan (BCBS, etc)	10%	8%	12%	3%	4%	3%	17%	10%	20% J
DHS / Iowa Medicaid Enterprise for Iowa Medicaid Members	13%	12%	12%	6%	8%	5%	21%	15%	16%
Friends	11%	12%	11%	13%	8%	13%	10%	15%	8%
Newspapers/Magazines	11%	20%	11%	9%	28% DF	10%	14%	15%	10%
Medicare	8%	12%	11%	9%	20% DF	5%	7%	8%	16%
Library	10%	5%	10%	3%	12%	8%	17% J	0%	10% J
Disability Service Providers	16%	12%	9%	16% F	16% F	5%	17%	10%	12%
Television	3%	8%	9%	6%	8%	13%	0%	8%	4%
Amerigroup – Managed Care Organization for Iowa Medicaid members	3%	5%	7%	0%	8%	10% D	7%	3%	6%
Iowa Department of Vocational Rehabilitation	10%	8%	7%	6%	8%	3%	14%	8%	12%
Public Health Department	5%	5%	5%	9%	4%	0%	0%	5%	10% H
Mailing Lists	8%	2%	5%	6%	4%	8%	10% J	0%	4%
Work	10%	6%	4%	6%	0%	3%	14%	10%	6%
School	2%	0%	3%	3%	0%	8%	0%	0%	0%
Radio	5%	0%	2%	6%	0%	0%	3%	0%	2%
Department of Veterans Affairs	2%	3%	2%	3%	8%	0%	0%	0%	4%
Church	3%	0%	1%	6%	0%	0%	0%	0%	0%
Amerihealth Caritas – Managed Care Organization for Iowa Medicaid members	5%	0%	1%	3%	0%	0%	7%	0%	2%
Other	23% B	8%	15%	28% EF	8%	13%	17%	8%	18% J

Q2: First, where do you get most of your health information? n220

*A/B/C indicate number is at least 10% **higher** than corresponding Total data point

*D/E/F indicate number is at least 10% **higher** than corresponding Person with BI data point

*H/J/K indicate number is at least 10% **higher** than corresponding Family Member data point

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Want Community to Understand – Year-Over-Year Comparison

	Total			Person with BI			Family Member			Caregiver		
	2017	2018	2019	2017	2018	2019	2017	2018	2019	2017	2018	2019
n	116	114	153	32	25	40	29	39	50	55	50	63
A	B	C	D	E	F	H	J	K	L	M	N	
Brain injury frequently results in challenges and disabilities that others cannot necessarily see	84%	86%	81%	84% F	92% F	70%	93%	87%	88%	78%	82%	83%
Daily functioning can vary depending on symptoms that are easily affected by stress or medical symptoms	66%	61%	67%	69% E	48%	70% E	55%	69% H	64%	69%	60%	68%
Individuals with memory or language changes are not less intelligent than before their brain injury	54%	47%	60% B	50%	56%	63% D	48%	44%	54% J	60% M	46%	63% M
Brain injury results have different outcomes and everyone has unique symptoms	62%	58%	59%	47%	44%	48%	69% J	59%	64%	67%	64%	62%
After brain injury, the individual may never be the same person they were before	59%	63%	58%	69% F	76% F	55%	59%	62%	70% H	55%	58%	49%
People with brain injury do not need pity but do need compassion and respect	46%	56% A	54%	47%	60% DF	50%	45%	56% H	54%	45%	54%	56% L
My "main goal" is to live in the community like anyone else as a "member" of my community	28%	39% A	31%	22%	40% D	33% D	31%	41% H	34%	31%	36%	27%
To be more aware of the consequences of brain injury	31%	36%	27%	34%	28%	40% E	45% K	38% K	16%	22%	38% LN	27%
Brain injury impacts how I express myself	34% BC	23%	24%	56% EF	36%	40%	17%	31% H	28% H	29% MN	10%	11%
To be more aware about how brain injury can be prevented	24%	17%	20%	13%	12%	18%	24% JK	5%	14%	31%	28%	25%

Q6: Again, using the list below, which of the following are **most important** to you when it comes to what you want your community to better understand about brain injury? n383

*A/B/C indicate number is at least 10% **higher** than corresponding Total data point

*D/E/F indicate number is at least 10% **higher** than corresponding Person with BI data point

*H/J/K indicate number is at least 10% **higher** than corresponding Family Member data point

*L/M/N indicate number is at least 10% **higher** than corresponding Caregiver data point

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Future Improvements – Year-Over-Year Comparison

	Total			Person with BI			Family Member			Caregiver		
	2017	2018	2019	2017	2018	2019	2017	2018	2019	2017	2018	2019
n	116	114	153	32	25	40	29	39	50	55	50	63
A	B	C	D	E	F	H	J	K	L	M	N	
Services (funding, duration, scope and/or intensity)	53%	46%	50%	34%	28%	45% DE	45%	54% K	36%	67% M	48%	65% M
Training and education for family members and / or caregivers	31%	37%	44% A	22%	28%	30%	41%	38%	58% HJ	31%	40%	41% L
Access to Medicaid waiver for brain injury	54% BC	40%	43%	56% EF	32%	28%	48% J	33%	50% J	56%	50%	48%
Access to community based support and services	47% B	35%	43%	41% EF	20%	30% E	45% J	33%	46% J	51%	44%	49%
Providers that specialize in brain injury (i.e. Community Based Neuro Behavioral Services)	42%	46%	43%	50% F	44%	38%	38%	59% H	54% H	40%	38%	38%
Training and education for professionals	34%	40%	39%	19%	20%	40% DE	38%	41%	36%	40%	50% L	41%
Training and education for survivors of brain injury	37%	29%	31%	44%	52% F	40%	41% JK	28%	26%	31% M	18%	30% M
Awareness of brain injury	16%	19%	23%	22%	28%	23%	7%	18% H	24% H	16%	16%	22%
Information on living well with brain injury	34% C	29%	20%	50% F	48%	40%	41% JK	23% K	12%	22%	24% N	13%
Advocacy services (such as BIAIA, Ombudsmans office)	13%	19%	19%	13%	36% DF	18%	10%	10%	26% HJ	15%	18%	14%
Medical care	16%	18%	18%	13%	28% D	23% D	14%	23%	20%	20% M	10%	14%
Awareness of brain injury across the state	22%	24%	18%	25%	20%	25%	28% K	28% K	16%	18%	22%	14%
Access to Brain Injury Alliance of Iowa/Neuro Resource Facilitation	13%	12%	16%	9%	12%	15%	24% J	8%	20% J	9%	16%	14%
Brain injury services for individuals in the criminal justice system	14%	13%	14%	9%	0%	3%	10%	15%	10%	18%	18%	24%
Brain injury services for student with concussion or other brain injury	21%	26% C	14%	16%	16%	18%	14%	18% K	8%	27% N	38% LN	16%
Awareness of brain injury in my community	19%	18%	12%	22%	24%	18%	17%	21% K	8%	18%	14%	13%
Other improvements needed	5%	8%	6%	9%	12%	13%	3%	5%	4%	4%	8%	3%

Q16: What would you like to see improve about brain injury services in Iowa? n383

*A/B/C indicate number is at least 10% **higher** than corresponding Total data point

*D/E/F indicate number is at least 10% **higher** than corresponding Person with BI data point

*H/J/K indicate number is at least 10% **higher** than corresponding Family Member data point

*L/M/N indicate number is at least 10% **higher** than corresponding Caregiver data point

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Hardest Part – Year-Over-Year Comparison

	Total			Person with BI			Family Member			Caregiver		
	2017	2018	2019	2017	2018	2019	2017	2018	2019	2017	2018	2019
n	116	114	153	32	25	40	29	39	50	55	50	63
	A	B	C	D	E	F	H	J	K	L	M	N
Memory, language or thinking changes	59%	54%	55%	72% EF	56% F	43%	52%	54%	60%	55%	54%	59%
Emotional changes	43%	46%	43%	44%	36%	35%	38%	44%	42%	45%	52%	49%
Changes in ability to work	40% B	29%	41% B	41%	40%	55% DE	38% J	21%	34% J	40% M	30%	37%
Obstacles to services (waiting lists, transportation, etc.)	42%	42%	37%	13%	32% DF	13%	38% K	33%	28%	62%	54%	60%
Financial challenges	40%	33%	37%	44%	48%	45%	41%	33%	40%	36% M	26%	30%
Tremendous variability in outcomes for each individual – everyone's symptoms are unique	37%	43%	37%	3%	20% D	15% D	31%	36%	42% H	60% N	60% N	46%
Having to rely on others	33%	35%	35%	28%	20%	25%	48% J	38%	46%	27%	40% L	33%
Ability to complete daily tasks	28%	35%	34%	41%	32%	35%	31%	33%	32%	20%	38% L	35% L
Loneliness / Isolation	41%	37%	33%	28%	28%	23%	45%	49%	44%	45% MN	32%	30%
Fatigue	21%	27%	26%	41%	52% DF	40%	24%	26%	30%	7%	16%	14%
Dizziness, headaches, or other physical symptoms	20%	21%	20%	44% E	32%	48% E	17%	13%	12%	7%	22% LN	8%
Sleeping (too little or too much)	11%	16%	18%	28%	24%	45% DE	3%	21% HK	8%	5%	8%	10%
Fear of falling, balance issues	12%	16%	14%	28%	20%	25%	7%	23% H	14%	5%	8%	8%
Transportation	19%	16%	12%	16% F	20% F	3%	21%	13%	12%	20%	16%	19%
Driving	7%	7%	8%	3%	4%	15% DE	3%	13% H	12%	11% N	4%	0%
Other challenges than listed	10%	11%	8%	13%	12%	10%	10%	8%	10%	9%	14%	5%

Q18. In your opinion, what are the hardest or most challenging things about brain injury? You may rank up to 5 options. n383

*A/B/C indicate number is at least 10% higher than corresponding Total data point

*D/E/F indicate number is at least 10% higher than corresponding Person with BI data point

*H/J/K indicate number is at least 10% higher than corresponding Family Member data point

*L/M/N indicate number is at least 10% higher than corresponding Caregiver data point

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Want Disability Service Professionals to Understand – Year-Over-Year Comparison

	Total			Person with BI			Family Member			Caregiver		
	2017	2018	2019	2017	2018	2019	2017	2018	2019	2017	2018	2019
n	116	114	153	32	25	40	29	39	50	55	50	63
	A	B	C	D	E	F	H	J	K	L	M	N
Outcomes after brain injury are very different from person to person, each having unique symptoms	78%	75%	83%	75%	68%	80% E	86%	79%	84%	75%	76%	84%
Families and caregivers need reliable information, ability to offer input and support	67%	75%	70%	50%	64% D	60% D	83% K	87% K	70%	69%	72%	76%
Recovery and rehabilitation after brain injury doesn't always progress in the same steps or phases for everyone	75%	75%	68%	75%	72%	73%	59%	67% K	56%	84%	84%	75%
More understanding of brain injury and symptoms of brain injury	62%	66%	65%	66% E	56%	63%	59%	67%	70% H	62%	70%	63%
The benefits and need for ongoing professional education, training about symptoms, treatment and support	78% BC	68%	65%	72% EF	48%	55%	79% JK	69% K	54%	82%	78%	81%
Surviving a brain injury is hard, and requires your patience and respect	67%	66%	62%	78%	88% DF	75%	52%	59%	66% H	69% N	60%	51%
Sometimes people with brain injury need a good advocate	57%	60%	59%	66%	88% DF	65%	59%	62%	66%	51%	44%	51%

Q4: And, using the following list, which of the following are most important to you when it comes to what you want disability service professionals to better understand about brain injury? n383

*A/B/C indicate number is at least 10% higher than corresponding Total data point

*D/E/F indicate number is at least 10% higher than corresponding Person with BI data point

*H/J/K indicate number is at least 10% higher than corresponding Family Member data point

*L/M/N indicate number is at least 10% higher than corresponding Caregiver data point

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Past Year Improvements – Year-Over-Year Comparison

	Total			Person with BI			Family Member			Caregiver		
	2017	2018	2019	2017	2018	2019	2017	2018	2019	2017	2018	2019
n	116	114	153	32	25	40	29	39	50	55	50	63
	A	B	C	D	E	F	H	J	K	L	M	N
Access to Brain Injury Alliance of Iowa/Neuro Resource Facilitation	45% C	39%	35%	53% EF	32% F	18%	45% J	33%	42%	40%	46%	41%
Awareness of brain injury across the state	29%	29%	30%	22%	20%	15%	24%	31%	36% H	36%	32%	35%
Brain injury services for student with concussion or other brain injury	28%	25%	30%	6%	16% D	15%	17%	21%	32% HJ	45% M	34%	38%
Advocacy services (such as BIAIA, Ombudsman's office)	36% B	25%	29%	34% EF	20%	18%	38%	36%	36%	36% M	20%	32% M
Providers that specialize in brain injury (i.e. Community Based Neuro Behavioral Services)	28%	20%	22%	28% F	28% F	10%	24% J	10%	20% J	31%	24%	30%
Awareness of brain injury in my community	23%	19%	20%	19%	24%	15%	14%	10%	16%	31%	24%	25%
Medical care	12%	13%	18%	19%	16%	23%	17%	15%	20%	5%	10%	14%
Access to community based support and services	13%	16%	18%	19%	20%	18%	10%	13%	18%	11%	16%	17%
Brain injury services for individuals in the criminal justice system	7%	3%	3%	0%	4%	3%	3%	0%	2%	13% N	4%	3%
Other (please specify)	15%	15%	14%	19% E	8%	20% E	7%	13%	4%	16%	20%	19%
Nothing has improved	16%	16%	16%	19%	28%	33% D	28% K	23% K	10%	9%	4%	11%

Q14. Now, thinking about brain injury services in Iowa, which of the following have improved in the past year? n383

*A/B/C indicate number is at least 10% **higher** than corresponding Total data point
 *D/E/F indicate number is at least 10% **higher** than corresponding Person with BI data point
 *H/J/K indicate number is at least 10% **higher** than corresponding Family Member data point
 *L/M/N indicate number is at least 10% **higher** than corresponding Caregiver data point

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Useful Brain Injury Alliance Newsletter Information – Year-Over-Year Comparison

	Total			Person with BI			Family Member			Caregiver		
	2017	2018	2019	2017	2018	2019	2017	2018	2019	2017	2018	2019
n	116	114	153	32	25	40	29	39	50	55	50	63
	A	B	C	D	E	F	H	J	K	L	M	N
Newsletter	57%	59%	55%	59% F	52% F	35%	52%	62% H	64% H	58%	60%	60%
Tips	41%	47%	45%	34%	56% D	50% D	48%	49%	42%	42%	42%	44%
Events	41%	44%	42%	38%	52% DF	38%	48% J	28%	40% J	38%	52% L	48% L
Research and Science	55% C	49%	42%	56% F	52% F	40%	55% JK	41%	44%	55% N	54% N	43%
Support Group	41%	33%	39%	50% E	36%	43%	45%	46%	38%	33% M	22%	37% M
Survivor Stories	40%	32%	37%	41%	48% F	35%	48% J	28%	42% J	35%	26%	33%
Iowa System Updates	38%	35%	33%	19%	36% DF	23%	41% J	31%	32%	47%	38%	40%
Action Alerts	39% C	35%	28%	22%	28%	20%	48% JK	33%	24%	44%	40%	37%
Other	9%	11%	12%	6%	16% D	18% D	7%	13%	14%	13%	8%	6%

Q26. What information from the Brain Injury Alliance of Iowa newsletter, social media, and electronic mailings do you find useful? n383

*A/B/C indicate number is at least 10% **higher** than corresponding Total data point
 *D/E/F indicate number is at least 10% **higher** than corresponding Person with BI data point
 *H/J/K indicate number is at least 10% **higher** than corresponding Family Member data point
 *L/M/N indicate number is at least 10% **higher** than corresponding Caregiver data point

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Brain Injury Alliance
I O W A

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